



July 8, 2019

Ms. Maria Roat, Chief Information Officer, Small Business Administration  
Ms. Karen Dunn Kelley, Deputy Secretary, Department of Commerce  
Ms. Suzette Kent, Federal Chief Information Officer, Office of Management and Budget, Office of the Federal Chief Information Officer  
Ms. Nancy Potok, Chief Statistician of the U.S., Office of Management and Budget, Office of Information and Regulatory Affairs  
Mr. Kelvin Droegemeier, Director, Office of Science and Technology Policy

Re: Federal Data Strategy Action Plan

Submitted electronically at: <https://strategy.data.gov/action-plan/#federal-data-strategy-action-plan>

Dear Leveraging Data as a Strategic Asset CAP Goal Co-leads:

The American Medical Informatics Association (AMIA) appreciates the opportunity to provide input regarding the Draft Federal Data Strategy Action Plan.

Health informatics is a nearly 60-year-old field of study concerned with data collection, analysis, and application within broad domains of health, including healthcare delivery, public health, consumer health, clinical research, and translational research. AMIA is the professional home for more than 5,500 health informatics professionals, representing front-line clinicians, researchers, educators, and public health experts who bring meaning to data, manage information, and generate new knowledge focused on improving health. As the voice of the nation's health informatics professionals, AMIA members advance health and wellness by evaluating information and communication technology interventions, innovations, and public policy across care, research, and community settings.

AMIA strongly supported development of this strategy and we provided input<sup>1</sup> in July 2018, offering several recommendations that subsequently have been incorporated into final Principles and Practices, and are reflected in this draft Action Plan. AMIA considers the coordinated management of federal data and information a national imperative. We note that this strategy builds on a long pedigree of federal efforts to manage federal data as an asset, stretching across decades of policy. Among more than a dozen official actions of federal legislation, regulation, and directives are the convictions often expressed by and for the American public that their data should be secure, private, and appropriately leveraged for public benefit. These same actions dictate that administrative data produced by the federal government should be accessible, discoverable, and usable by the public.

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<sup>1</sup> AMIA Comments to Federal Data Strategy, July 2018. Available at: [https://www.amia.org/sites/default/files/AMIA-Response-to-Draft-Federal-Data-Strategy\\_0.pdf](https://www.amia.org/sites/default/files/AMIA-Response-to-Draft-Federal-Data-Strategy_0.pdf)

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We support several aspects of the draft Action Plan towards these goals, including the framing of Action items in the proposed three categories: Government-wide Data Services; Cross-Agency Collaboration; and Agency Activities. Specifically, we offer the following recommendations:

Action 1: Create an OMB Data Council – AMIA supports the creation of such a council and given that “OMB’s efforts to ensure relevant participants are engaged in data governance will be a model for individual agencies,” we strongly recommend that citizens representing consumers be included as part of government-wide and agency-specific information policy development activities. Consumer views will be important to understand and incorporate at all levels of the Strategy. By designating specific seats on the Council, OMB would signal the importance of such views to federal agencies by example.

Action 2: Develop a Curated Data Science Training and Credentialing Catalog – AMIA is a strong advocate for training and educational activities in health informatics. Many of the core competencies, skills, and knowledgebase of health informatics can be similar to those of data and information management and data science and analytics. We are the professional home for health informatics and are eager to share our educational and training offerings with those federal employees who may benefit.

Action 3: Develop a Data Ethics Framework – AMIA strongly supports development of such a framework at the government-wide level. A 2018 AMIA White Paper<sup>2</sup> articulated that “decisions related to data access and data sharing are fundamental expressions of social and ethical norms in a modern, connected society,” and that “public policy should encourage socially responsible and ethically consistent data access and data sharing.” We see these values expressed in Action 3 and we encourage that this framework (1) be developed to also reflect the values of citizens/consumers and (2) that its implementation require a thorough analysis of both the anticipated benefits and potential unintended consequences of activities related to the implementation of the Strategy.

Action 8: Pilot Standard Data Catalogs for Data.gov – AMIA appreciates the inclusion of this Action item given our prior recommendation to: (1) publish data dictionaries; and (2) harmonize data dictionaries across agencies. We noted that data dictionaries that identify the element name, data type, and meaning for each data point in a database must be published so both the public and other federal agencies can interpret the data. In addition, these data dictionaries should align across agencies. For example, a field called ‘Zip’ in one data set should not be called ‘zip code’ in another. AMIA recommended that this Strategy initiate a collaborative, inter-agency consensus process to ensure that data elements used by disparate agencies – but which refer to the same concept – are named the same everywhere. We view the cross-agency collaborations articulated in this draft Action Plan as a step in that direction (please see below for more comments on the Cross-Agency Collaboration Actions).

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<sup>2</sup> Redefining our Picture of Health: An AMIA Policy Invitational White Paper. 2018. Available at: <https://www.amia.org/sites/default/files/API-2017-White-Paper-Redefining-our-Picture-of-Health.pdf>

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Action 9: Improve Data Resources for AI Research and Development – AMIA provided input<sup>3</sup> to the recently updated National Artificial Intelligence Research and Development Strategic Plan.<sup>4</sup> We very much support inclusion of this Action item as a cross-agency collaboration. Specifically, we recommend this effort: (1) Proceed with developing an implementation framework based on the existing strategic areas and associated aims, supplementing the existing strategy; (2) Emphasize AI R&D investments in areas of strong societal importance that are not aimed at consumer markets, especially relating to human-AI collaboration and the ethical, legal, and societal implications of AI with additional emphasis on malicious AI; (3) Direct cabinet-level Departments to produce annual reports articulating how their AI R&D efforts contribute to the federal AI R&D strategy; and (4) Study the national landscape for creating and sustaining a healthy AI R&D workforce with an emphasis on both general-purpose AI R&D experts as well as domain-specific AI R&D experts.

Action 13: Assess Data and Related Infrastructure Maturity & Action 16: Identify Priority Datasets for Agency Open Data Plans – AMIA encourages the OMB Data Council to focus efforts on helping Agencies fulfill these Action items in a consistent, comparable way so that improvements and benchmarks can be easily understood.

**Finally, AMIA recommends an additional Action item under Cross-Agency Collaboration to “Improve Health and Human Services Data Standards.”** We understand the importance of data standards for financial management and geospatial applications and see those as good examples of where cross-agency collaboration is needed. However, we also note that an already significant and increasing portion of the US economy and federal spending is dedicated to health, healthcare delivery, and research. The number of federal programs that support these activities is also growing and there is an urgent need to improve data standards for health programs, including development of common data elements and consistent use of data standards vocabularies.

We reiterate our support for this plan and AMIA stands ready to help ensure this effort has the requisite expertise to accomplish these worthy goals. We have provided details to our key recommendations and provided additional information in the enclosed document. Should you have any questions or require additional information, please contact AMIA Vice President for Public Policy Jeffery Smith at [jsmith@amia.org](mailto:jsmith@amia.org) or (301) 657-1291 ext. 113. We look forward to continued dialogue.

Sincerely,

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<sup>3</sup> <https://www.amia.org/sites/default/files/AMIA-Response-to-AI-Research-and-Development-Strategic-Plan-RFI.pdf>

<sup>4</sup> National Artificial Intelligence Research and Development Strategic Plan: 2019 Update. Available at: <https://www.whitehouse.gov/wp-content/uploads/2019/06/National-AI-Research-and-Development-Strategic-Plan-2019-Update-June-2019.pdf>

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